



Justice Center

THE COUNCIL OF STATE GOVERNMENTS

The Role of 988 in Supporting People with Intellectual and Developmental Disabilities (IDD)

December 14, 2022 | 3:00–4:30 p.m. ET | The Arc of the United States | Leigh Ann Davis and Carlean Ponder

Presentation Outline

- I. Welcome and Introductions
- II. Intersectionality of Crisis Response, Disability, and Black Indigenous and People of Color (BIPOC)
- III. Understanding the Role of 988 in Crisis Response for People with IDD
- IV. Creating Inclusive 988 Response Systems
- V. Questions and Answers

Speakers

- Leigh Ann Davis, *Senior Director, Disability and Justice Initiatives, The Arc of the U.S.*
- Felicia Lopez Wright, *Senior Policy Analyst, Behavioral Health Division, The Council of State Governments (CSG) Justice Center*
- Carlean Ponder, *Director of Disability Rights and Housing Policy, The Arc of the U.S.*

The Council of State Governments Justice Center

We are a national nonprofit, nonpartisan organization that combines the power of a membership association, serving state officials in all three branches of government, with policy and research expertise to develop strategies that increase public safety and strengthen communities.

How We Work

- We bring people together
- We drive the criminal justice field forward with original research
- We build momentum for policy change
- We provide expert assistance

Our Goals

Break the cycle of incarceration

High rates of recidivism increase taxpayer costs, diminish public safety, and tear apart families and communities. We work with partners inside and outside of government to reduce crime and incarceration among youth and adults in contact with the justice system.

Advance health, opportunity, and equity

Efforts to make communities safer and healthier are hampered by insufficient behavioral health services, barriers to economic mobility, homelessness, lack of support for victims, and racial and gender inequity. We bring people from diverse systems and perspectives together to improve policy and practice related to these challenges.

Use data to improve safety and justice

Data holds the power to help us understand and change justice systems for the better. And yet, states and counties still know far too little about how their systems perform. Our work transforms information into meaningful insights for policymakers.

Equity and Inclusion Statement



The Council of State Governments Justice Center is committed to advancing racial equity internally and through our work with states, local communities, and Tribal Nations.



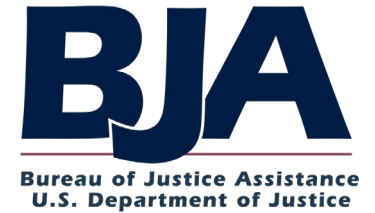
We support efforts to dismantle racial inequities within the criminal and juvenile justice systems by providing rigorous and high-quality research and analysis to decision-makers and helping stakeholders navigate the critical, and at times uncomfortable, issues the data reveal. Beyond empirical data, we rely on stakeholder engagement and other measures to advance equity, provide guidance and technical assistance, and improve outcomes across all touchpoints in the justice, behavioral health, crisis response, and reentry systems.

Justice and Mental Health Collaboration Program

The Justice and Mental Health Collaboration Program (JMHCP) promotes innovative cross-system collaboration and provides grants directly to states, local governments, and federally recognized Indian Tribes. It is designed to improve responses to people with mental health conditions and substance use disorders who are involved in the criminal justice system.

The U.S. Department of Justice Bureau of Justice Assistance

Mission: BJA's mission is to provide leadership and services in grant administration and criminal justice policy development to support state, local, and Tribal justice strategies to achieve safer communities. BJA works with communities, governments, and nonprofit organizations to reduce crime, recidivism, and unnecessary confinement, and promote a safe and fair criminal justice system.



Visit the [BJA website](#) to learn more.

The National Center on Criminal Justice and Disability



Training and technical assistance
for criminal justice professionals



Information and referral
for people with disabilities and their families



Resource collection and creation
including white papers, fact sheets, and articles



Education
social media, webinars, and conferences



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Definition of Intellectual and Developmental Disabilities (IDD)

- Physical and/or mental impairments that begin before age 22
- Substantial functional limitations in at least 3 of these:
 - Self-care
 - Learning
 - Walking/moving around
 - Self-direction
 - Independent living
 - Economic self-sufficiency

People with IDD in the Criminal Justice System

- People with IDD represent 4–10 percent of the prison population.
- 2 in 10 people in prison and 3 in 10 people in jail report having a cognitive disability.
- People with IDD experience the highest rate of victimization compared to other types of disabilities.
- 65–70 percent of youth involved in the justice system have a disability (3x higher than the national rate).

Data on Intersectionality

- Between 2013 and 2015, one-third to one-half of people shot and killed by the police in the U.S. had a disability.
- An *American Journal of Public Health* article found that young people with disabilities are 13 percent more likely to be arrested than their peers without a disability.
 - This figure jumps to 17 percent for Black youth with disabilities.
- People with disabilities have an overall 43 percent chance of arrest, with young Black men experiencing more disproportionality.

For sources, see slide 38.

Co-occurring IDD and Mental Illness

- 30–40 percent of people with IDD have a co-occurring mental health diagnosis; substance use disorder is estimated at 20 percent in people with IDD and mental health disorder.
- Mental health conditions in people with IDD may be overlooked because
 - The person may find it hard to describe their feelings or experiences;
 - The signs or symptoms may not be obvious or present all the time;
 - The person may be taking medicines that affect their feelings or behavior;
 - It may be difficult to tell if the behavior has happened in the past and to recognize patterns of mental health conditions; and/or
 - Mental health symptoms may be similar to other types of disability, such as autism spectrum disorder.

For sources, see slide 39.

Stories Behind the Statistics

“Stephon Watts, a 15-year-old African American teen that was diagnosed with Asperger’s Disorder, had ten previous interactions with Calumet City Illinois Police within two years, including at least one where police discharged tasers to subdue him...Watts’ father called the police after arguing with his son, who didn’t want to go to school, having been instructed by Social Workers that Watts should be handled by authorities when agitated. Police say they found Watts armed with a knife in the basement of his parents’ home. When one officer sustained a defensive wound to his left forearm, two other officers on the scene fired their weapons. Steven Watts, Stephon’s father, says his son was shot once in the leg, and then again in the head.”

“Stephon Watts, Autistic Teen, Fatally Shot By Police In His Home (VIDEO),” Huffpost, accessed November 18, 2022, https://www.huffpost.com/entry/stephon-watts-autistic-te_n_1249695.

Crisis Response Services for People with IDD

- Robust research and evaluation are needed across the continuum of crisis response services for people with IDD.
- Without evidence-based tools, programs and training solutions are unsustainable.

Amy C. Watson, Michael T. Compton, and Leah G. Pope, *Crisis Response Services for People with Mental Illnesses or Intellectual and Developmental Disabilities: A Review of the Literature on Police-based and Other First Response Models* (New York: Vera Institute of Justice, 2019).

Crisis Response Services for People with Mental Illnesses or Intellectual/Developmental Disabilities: A Review of the Literature on Police-Based and Other First Response Models

October 2019
Fact Sheet

Many converging factors have contributed to the need for community-based crisis and emergency responses for people with serious mental illnesses (SMI), those having psychiatric crises, and those who have intellectual or developmental disabilities (I/DD). Police-based and related crisis response services for people with SMI, I/DD, or both can play a vital role in reducing justice system contact and improving health outcomes among these vulnerable populations. The Serving Safely initiative of the Vera Institute of Justice (Vera) works to improve interactions between law enforcement and people with mental illnesses and I/DD. The initiative's Research and Evaluation Committee developed this literature review as a first step toward creating a research agenda for the field that identifies knowledge gaps and prioritizes options for scalable research and evaluation.

An overview of the approaches reviewed

The models and approaches described in the review have typically been designed and implemented for people who have SMI or those with I/DD; remarkably few studies have considered both groups. Most research has focused on models and other approaches developed for people with mental illnesses or having a psychiatric crisis. The need for further research on the same or different approaches for those who have I/DD is compelling.

Vera's review includes only the models and approaches that can be implemented at the local level and that generate a response to a person in need in the community. It is limited to those responses at the *first intercept* (meaning pre-arrest or at the first point of contact with the criminal justice system). It focuses on the following nine models and approaches.

Case management services. For the purposes of the review, the case management teams of interest pair behavioral health professionals with officers to address people who are considered "high utilizers" of police and other emergency services. The authors found several reports that provide program descriptions and some preliminary findings on the impact of this approach, but no peer-reviewed research.

Co-responder teams. Programs within this overarching model typically pair an officer with a mental health professional to respond to people in the community who are experiencing a mental health crisis. The literature suggests that this model may have value for responding to people experiencing mental health crises in the community and reducing unnecessary emergency department visits—and perhaps reducing the number of repeated calls for service. Significant variation in implementation makes it difficult to generalize findings



For more information

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The Vera Institute of Justice is a justice reform change agent. Vera produces ideas, insights, and research that inspire change in the systems people rely upon for

safety and justice, and works in close partnership with government and civic leaders to implement it. Vera is currently pursuing core priorities of ending the misuse of jails, transforming conditions of confinement, and ensuring that justice systems more effectively serve America's increasingly diverse communities. For more information, visit www.vera.org.

To read the full report, visit <http://www.vera.org/crisis-response-services>. For more information about the report, contact Leah Pope, senior research fellow, at lpope@vera.org.

Improving Outcomes for People in Contact with the Criminal Justice System Who Have IDD

Consider the value of partnerships when creating 988 response systems.

“Partnering with stakeholders, comprised of individuals from the IDD community can help criminal justice administrators better understand the needs of people with IDD and increase their access to services.”

Jazmone Wilkerson, Felicia Lopez-Wright, and Leigh Ann Davis, *Improving Outcomes for People in Contact with the Criminal Justice System Who Have Intellectual or Developmental Disabilities*, (New York: The Council of State Governments Justice Center, 2022).

Field Notes | Behavioral Health

April 2022

Improving Outcomes for People in Contact with the Criminal Justice System Who Have Intellectual or Developmental Disabilities

Historically, people with intellectual or developmental disabilities (IDD)—such as Down syndrome or autism spectrum disorder—have been both under and poorly served¹ in their communities. Jurisdictions often lack programs tailored to address the unique needs of people with IDD, as well as care providers who are trained to provide treatment. Similarly, when people with IDD encounter or are involved in the criminal justice system, they often experience a system that is unable to address their unique needs² and face misconceptions about their abilities.

However, there are ways to help improve outcomes for people with IDD and reduce their chances of re-encountering the criminal justice system. This brief offers important steps that criminal justice administrators can take to better identify and respond to the needs of people with IDD.

1. Train all staff to identify people who have IDD.

Being able to quickly identify people who have IDD is not only imperative in providing appropriate supportive services, but it also aids in their ability to access the legal system and understand the judicial process. Additionally, this identification is a necessary part of complying with the Americans with Disabilities Act (ADA), which protects individuals with IDD from discrimination within the criminal justice system, in addition to other provisions.³ Therefore, professionals across the criminal justice system, from dispatch to reentry, should regularly receive training on ways to identify if someone has an IDD, how to meet ADA compliance measures, and any updated policies.

For example, officers and other first responders who make initial contact should be trained to properly ask questions that can help them identify if a person has an IDD. Potential questions can include the following:

- Do you get any money from the government or social services, such as Supplemental Security Income (SSI) or Medicaid?
- Have you ever attended special education classes?
- What is something you are good at? What is something you need help with or struggle doing?
- You may need to fill out some forms today. Do you need help with this? How can I help you? Is there any other assistance you need?
- When you need to make decisions, does anyone help you, such as a legal guardian? Is there someone I should call to help you right now?

Staff should also be trained to observe whether the person is having difficulty understanding, responding, or communicating while answering any of these questions and if they need more time to respond. One way to confirm understanding is by asking individuals to repeat what is being said in their own words.

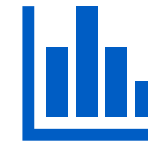
2. Create policies for engaging with and responding to people with IDD.

When criminal justice system staff encounter a person who may have an IDD, they should have policies in place that inform proper interaction. IDD policies should include: (1) language on de-escalation;⁴ (2) information about use of person-centered and inclusive language;⁵ and (3) guidance on appropriately accommodating, interacting, and communicating with people with IDD. For example, policies should indicate that screenings do not occur in open areas, which can often be loud and distracting for people with IDD and could make it more challenging for them to answer questions. Open area screenings also risk public disclosure of a disability, which can lead to increased stigmatization and risk of victimization. Criminal justice administrators should ensure these policies are regularly updated and informed by program evaluation and disseminated to all staff in a clear manner.

Crisis Response and Disability Resources

- [The Arc's BIPOC Disabled Recorded Event](#)
- The Arc's National Center on Criminal Justice and Disability [*Pathways to Justice Training*](#)
- [Academic Training Project](#) (funded by Bureau of Justice Assistance)
 - Two-page publications for law enforcement on [understanding IDD and co-occurring disabilities](#) and [how to improve interactions](#)
 - [Responses to People with Behavioral Health and DD: A Review of Research on First Responder Models](#)
 - Coming Soon!
 - Steps for Deflection or Pre-arrest Diversion
 - [Crisis Response Intervention Training \(CRIT\)](#)

Polling Question: 988 Status



What is the current status of 988 in your state/area?

- We are in the planning stages of 988 implementation
- We are currently implementing 988
- 988 is live, but not enough resources to implement it well
- Most are still unaware of 988 in my area

If you have a different response, please share it in the chat

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The Origin of 988

- The first nationwide three-digit emergency phone number (911) was created in 1968.
- In October 2020, The National Suicide Hotline Designation Act of 2020 was signed into law.
- In a historic move, the U.S. Congress passed bipartisan legislation designating the number 988 as a nationwide mental health crisis response number.

Randy Ross, "[Closing the 911 Funding Gap: Increasing Revenues for 911 Emergency Dispatch Centers](#)," *Certified Public Manager Applied Research* 1 no. 1 (2020): 1.

Federal 988 Legislation

- Requires phone service providers to direct all 988 calls to the existing National Suicide Prevention Lifeline.
- Permits a fee/charge associated with mobile or IP-enabled devices. States can choose whether to levy this fee. The fee can pay for effective routing of calls to an appropriate crisis center and personnel and stabilization services directly responding to 988 calls.
- The Substance Abuse and Mental Health Services Administration (SAMHSA) must ensure the hotline is equipped to provide specialized resources to high-risk populations.

Federal Communications Commission, *[Designating 988 for the National Suicide Prevention Lifeline](#)* (Washington, DC: Federal Communications Commission, 2020).

988 and Accessibility for People with Disabilities

- 988 currently serves teletypewriter (TTY) users either through their preferred relay service or by dialing 1-800-273-8255.
- 988 also offers services through chat and text but only in English.
- 988 is in the process of expanding to videophone service to better serve people that are Deaf or Hard of Hearing.

Federal Communications Commission, *[Designating 988 for the National Suicide Prevention Lifeline](#)* (Washington, DC: Federal Communications Commission, 2020).

988 and Servicing People with IDD

SAMHSA (the federal agency overseeing 988 implementation) has not directly addressed the unique needs of people with IDD when seeking hotline services.

Hotline operators would need to be mindful of the following:

- Adjust the pace of therapy and the number of ideas or themes addressed, use basic rather than abstract concepts, and reduce complexity in language.
- Best practice is to provide basic awareness training for all 988 hotline operators, which includes the ability to identify people with IDD as callers, and to have preexisting arrangements with specialized services—such as Virginia’s REACH program: <https://dbhds.virginia.gov/developmental-services/crisis-services/>.

“Regional Education Assessment Crisis Services Habilitation,” Virginia Department of Behavioral Health and Developmental Services, accessed November 17, 2022, <https://dbhds.virginia.gov/developmental-services/crisis-services/>.

Virginia REACH Case Study

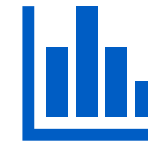
- The first state in the country to pass legislation to fund a 988 hotline
- Virginia has a crisis system for people with IDD called REACH that offers 24/7 crisis line and mobile crisis support and short-term crisis stabilization placements.
- REACH Hotline Number Operational Questions:
 - Will callers with IDD who dial 988 be connected to the REACH line?
 - How will 988 operators identify people with IDD who may be better served through REACH?
 - If mobile crisis services are needed, will the REACH services be utilized for people with IDD?
 - Does the REACH program have the hotline and mobile crisis capacity to serve calls initiated with 988? Has additional funding and staffing been considered for this program to seamlessly operate with 988?

For sources see slide 40.

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Polling Question: 988 and IDD



Are people with IDD included in 988 planning or discussions in your state/locality?

- Yes
- No
- Unsure
- There are plans in place to involve people with IDD

If you have a different response, please share it in the chat.

988 and Outreach to Specific Populations

- In September 2022, SAMHSA announced a pilot program to offer specialized call, text, and chat supports for lesbian, gay, bisexual, transgender, queer, questioning, and other sexual and gender minority (LGBTQI+) youth and young adults.
- What components are necessary to include youth with IDD and other disabilities?
 - Such as partnering with specialized organizations who can answer calls/text/video messages with appropriate cultural competency (e.g., The Trevor Project, REACH program in VA)

"988 Frequently Asked Questions," Substance Abuse and Mental Health Services Administration, accessed November 17, 2022, <https://www.samhsa.gov/find-help/988/faqs>.

988 and Outreach to Specific Populations (cont.)

- Washington State allocated funding received from the American Rescue Plan Act (ARPA) to assign mobile crisis teams dedicated to youth and young adults to respond to 988 calls requiring on-the-ground assistance. The plan included a minimum of six children and youth mobile crisis teams.
- Such a resource could serve youth and their families with disabilities by stabilizing youth in their homes and not in the emergency room.

Washington State Health Care Authority, *Spending Plan for the Implementation of the American Rescue Plan Act of 2021, Sect. 9817* (Washington: Washington State Health Care Authority, 2021).

988 and Outreach to Specific Populations (cont.)

- We recommend partnering with an IDD provider to access specialized hotline assistance and mobile crisis units for people with IDD and other disabilities. This requires ensuring that the state department of developmental disabilities is streamlined into crisis response systems and is fully staffed and funded.
- For special consideration of BIPOC youth, foster care-involved youth, and youth with disabilities, see the panel discussion on *Crisis Response for Young People with Disabilities*, which was hosted by The Arc of the U.S.

Washington State Health Care Authority, *Spending Plan for the Implementation of the American Rescue Plan Act of 2021, Sect. 9817* (Washington: Washington State Health Care Authority, 2021).

988 and Responses to BIPOC

- SAMHSA states that improving cultural competency is a key factor in the ongoing development of 988.
- BIPOC may avoid calling 988 due to the potential for law enforcement involvement in crisis response calls.
 - A report from The National Council on Disabilities highlighted incidents where phone calls to 988 resulted in welfare check visits from armed law enforcement and/or involuntary hospitalizations.

National Council on Disability, *[The Impact of COVID-19 on People with Disabilities](#)* (Washington, DC: National Council on Disability, 2021).

988 Launched, Now What?

- 988 launched nationwide in July 2022.
- In September 2022, SAMHSA reported a 45 percent increase in overall call volume and an improvement in answer rates and wait times compared to a year ago.
- Congress proposed federal legislation aimed at increased funding for 988 and building additional wraparound services such as mobile crisis teams.
 - Senators Baldwin (D-WI) and Collins (R-ME) introduced the 988 Coordination and Improvement Act (S. 4871).
 - The House of Representatives recently passed the Mental Health Justice Act sponsored by Representative Katie Porter (D-CA).

“HHS Secretary: 988 Transition Moves Us Closer to Better Serving the Crisis Care Needs of People Across America,” U.S. Department of Health and Human Services, accessed November 17, 2022, <https://www.hhs.gov/about/news/2022/09/09/hhs-secretary-988-transition-moves-us-closer-to-better-serving-the-crisis-care-needs-of-people-across-america.html>.

988 Launched: What Do We Need to Know?

- How are callers with IDD being identified?
- What forms of training are/have taken place to help hotline operators identify such callers?
- Has 988 identified partners in each state who can competently answer calls from people with IDD, service providers, and/or family members?
- What are the data collection points for your 988 hotline? Are you including metrics related to people with disabilities?
- How often are calls involving people with IDD transferred **from** 911 dispatch?

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Questions and Answers

Resources: Slide 13

- Joan Petersilia, *Doing justice? Criminal Offenders with Developmental Disabilities. Detailed Research Findings* (California: California Policy Research Center, 2000).
- Jennifer Bronson, Laura M. Maruschak, and Marcus Berzofsky, *Disabilities Among Prison and Jail Inmates: Special Report, 2011–12* (Washington, DC: Bureau of Justice Statistics, 2015),
<https://www.bjs.gov/content/pub/pdf/dpji1112.pdf>.
- Erika Harrell, *Crime Against Persons with Disabilities, 2009–2013-Statistical Tables* (Washington, DC: Bureau of Justice Statistics, 2015),
<https://www.bjs.gov/content/pub/pdf/capd0913st.pdf>.

Resources: Slide 14

- David M. Perry and Lawrence Carter-Long, *The Ruderman White Paper On Media Coverage Of Law Enforcement Use Of Force And Disability A Media Study (2013–2015) And Overview* (Massachusetts: Ruderman Family Foundation, 2016), https://rudermanfoundation.org/wp-content/uploads/2017/08/MediaStudy-PoliceDisability_final-final.pdf.
- Erin J. McCauley, "The Cumulative Probability of Arrest by Age 28 Years in the United States by Disability Status, Race/Ethnicity, and Gender," *American Journal of Public Health* 107, no. 12 (2017):1977–1981, <https://doi.org/10.2105/AJPH.2017.304095>.

Resources: Slide 24

- J. Salavert et al., “Substance use disorders in patients with intellectual disability admitted to psychiatric hospitalization,” *Journal of Intellectual Disability Research* 62, no. 11 (2018): 923–930.
- Valerie Bradley et al., *What Do NCI Data Reveal About People Who Are Dual Diagnosed with ID and Mental Illness?* (Cambridge, MA: Human Services Research Institute, 2019).

Resources: Slide 26

- “Virginia Is First State to Pass 988 Service Fee Legislation,” Crisis Now, accessed November 17, 2022, <https://talk.crisisnow.com/virginia-is-first-state-to-pass-988-service-fee-legislation/>.
- “Regional Education Assessment Crisis Services Habilitation,” Virginia Department of Behavioral Health and Developmental Services, accessed November 17, 2022, <https://dbhds.virginia.gov/developmental-services/crisis-services/>.

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For more information, please contact Felicia at
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